HRET Disparities Toolkit

A Toolkit for Collecting Race, Ethnicity, and Primary Language Information from Patients

H·RET
HEALTH RESEARCH &
EDUCATIONAL TRUST

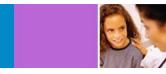# Table of Contents

HRET Disparities Toolkit

The Health Research and Educational Trust, with its partners, is pleased to present this toolkit for collecting race, ethnicity, and primary language information in health care organizations. It is designed to help hospitals, health systems, community health centers, health plans, and other potential users in understanding the importance of accurate data collection, assessing organizational capacity to do so, and implementing a framework designed specifically for obtaining information from patients/enrollees about their race, ethnicity, and primary (preferred) language efficiently, effectively, and respectfully.

For individual on-site technical assistance please contact Deborah Bohr, Senior Director, HRET, at **1-800-242-2407** or e-mail dbohr@aha.org.

The links below provide targeted information for a specific audience (stakeholder). By clicking on any one of the links (e.g. CEO, Clinical, etc.) you can access all the items in the table of contents. However, we designed the toolkit so you can look at information targeted specifically to your role or needs within your organization quickly. There is considerable overlap in the content for different audiences. We hope you will target the items in the table of contents that are most useful for you and find the toolkit easy to navigate.

- Chief Executive Officer
- Legal Affairs Department
- Quality Improvement Department
- Clinicians (doctors, nurses, other)
- Patient/Consumer
- Registration/Admission Staff
- Information Technology Department

Chief Executive Officer

Health care leaders are charged with advancing and managing individual organizational priorities. As hospitals and health care organizations work toward serving diverse populations, leaders must recognize the importance of understanding the unique characteristics of the communities they serve. Efforts to improve health care delivery require working with key staff. Leaders can be most effective by helping others develop the abilities and tools to come up with the best responses to problems and opportunities.

Improving the quality of care for everyone and eliminating health care disparities are central challenges facing our health care system. As emphasized by two recent Institute of Medicine reports, the need for better quality data about patients' race, ethnicity, and primary language is critical. The links below provide information to hospital and health system leaders about collecting race, ethnicity, and primary language information from patients.

Making the Case
Overview Presentation
Partners/Collaborators

Please refer to table of contents for more detailed information.

Legal Affairs Department

Hospitals and health care organizations need to be aware of legal and privacy issues regarding the collection of race, ethnicity, and primary language information from patients. The links below provide a

general overview addressing these issues and provide additional links for more detailed information. It is important to note that the collection of race, ethnicity, and primary language data is legal.

Legal Issues
Privacy/confidentiality

Please refer to the table of contents for more detailed information.

Quality Improvement Department

The ultimate goal for collecting information about patient race, ethnicity, and primary language is to improve the quality of care for all patients. Evidence indicates that quality improvement efforts, when linked to data on race and ethnicity, can improve quality of care and reduce health care disparities. The links below provide background information and tools (questionnaires) to help hospitals assess their current practices regarding race, ethnicity, and language data collection and surveys to determine whether complete and accurate information is being collected from patients once the framework is implemented.

Making the Case
Overview Presentation
Hospital Assessment Survey
Validation Survey

Please refer to the table of contents for more detailed information.

Clinicians

Doctors, nurses, and other health care practitioners are central to the functioning of health care systems and to societies as a whole. However, few societies have been as racially, ethnically, and culturally diverse as ours, presenting challenges and opportunities. Each new wave of immigration reminds us of these challenges and opportunities. Doctors, nurses, and other clinical professionals who care for diverse populations need to incorporate knowledge about their patients' perceptions of illness and disease, diverse belief systems, individual preferences, communication styles, and preferred language into their individual encounters with them. In doing so, clinicians can provide the best possible care to their patients and equip them with appropriate resources. The need for accurate data is critical so hospitals can target the resources clinicians need (interpreter services, patient education materials, food, etc.) to provide quality health care to their patients. The links below provide background information about the importance of collecting information about patient race, ethnicity, and language and how to collect to the data.

Making the Case
Collecting the Data

Please refer to the table of contents for more detailed information.

Patient and Consumer

Patients should understand why they are being asked to provide information about their racial and ethnic background and language preference. Hospitals do not want to alienate patients by asking these questions. The information is collected to ensure that all patients get the best possible care. The links below provide information about why collecting this information is important, protecting privacy and

involving members of the community in the process. There is also a link to success stories of other hospitals that have started using a systematic method for collecting this information.

Making the Case
Privacy/Confidentiality
Community Involvement
Success Stories
Resources

Please refer to the table of contents for more detailed information.

Registration/Admission Staff

Patient registration/admission staff are usually the first point of contact for many patients. The links below provide information for registration/admission staff about asking patients to provide information about their race, ethnicity, and primary language and about how to ask for this information and respond to patients' concerns and questions.

Collecting the Data
Staff Training Presentation
Question/Answer Response Matrix Presentation
(addressing patients concerns)

Please refer to the table of contents for more detailed information.

Information Technology (IT) Department

The IT department and staff are key in implementing the framework for collecting patient race, ethnicity, and primary language data within a hospital. IT staff can identify infrastructure capacity and needs and are best able to integrate the necessary elements of the framework (codes, fields, etc.) into existing software. The links below provide different coding schemes for race and ethnicity data. The staff training link provides one example of a registration system that has incorporated the framework for data collection.

Collecting the Data

Examples of data coding schemes:
• CDC Code Set I
• CDC Code Set II
• OMB Code Set

Staff Training Presentation

Please refer to the table of contents for more detailed information.

Making The Case

Measurement and outcomes have become increasingly important for demonstrating the effectiveness of health care. Evidence from the last 20 years shows that racial, ethnic, and language-based disparities

remain present in health care. The Institute of Medicine (IOM) report *"Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care,"* issued in 2002, is one of several recent studies documenting such evidence. There is a clear need to document and improve the quality of care provided to vulnerable populations.

The need for data to track these disparities and develop effective programs to reduce and eliminate them is clear. Disparities in health care can be addressed through a quality of care framework if data on race, ethnicity, and primary language are available. According to the report "The Right to Equal Treatment" issued by Physicians for Human Rights, data collection has long been central to the quality assurance process.

The data may also help evaluate population trends and help ensure nondiscrimination on the basis of race and national origin, such as providing meaningful access for persons with limited English proficiency.

Between 1990 and 2000, the foreign-born population of the United States increased 44 percent to 28.4 million people, according to the U.S. Census Bureau. This figure—28.4 million—is 10 percent of the nation's total population, the highest percentage since 1930. People living in the United States speak over 300 different languages, and nearly 47 million people speak a language other than English at home, as reported by the U.S. Census Bureau (2003).

Several recent studies document how many non-English-speaking patients experience a reduced quality of life due to health-related issues. Studies also show that many of these populations lack trust in the health care system.

Most hospitals (82 percent) currently collect data on their patients' race and ethnicity, and 67 percent collect information on patients' primary language. However, the data are not collected in a systematic or standard manner and are often not shared, even within different departments within the same hospital. Organizations that collect accurate data can use this information to ensure they have sufficient language assistance services, develop appropriate patient education materials, and track quality indicators and health outcomes for specific groups to inform improvements in quality of care.

Below are quotes from members of the Consortium for Eliminating Health Care Disparities Through Community and Hospital Partnerships, and the National Advisory Panel. Members' quotes are from a meeting held on November 5, 2003, to articulate the rationale for developing a uniform framework for data collection and the importance of collecting data. The full meeting summary document can be viewed by clicking here.

"There are reactive reasons for collecting this information, such as measuring disparities in quality of care and utilization, but there are also proactive reasons for collecting this information, such as providing health care that is appropriate to a population. The distinction may be important to patients in terms of what matters and the message they want to hear. They may react more positively to a proactive desire rather than a reactive desire."
David Baker

"If we have a population where there are a lot of disparities, then that population is not available for the work force. This is not a population that functions
well . . . [This issue is] not just about physical health but about the health of society."
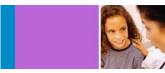**Jeannette E. South-Paul**

"Data has been a key problem at getting at disparities. The data is fractionalized . . . The way the data is fractionalized increases costs because you can't get resources to those communities that are at risk . . . [And] it's not just minority disparity, it's health disparity."
Gary Puckrein

"The major purchasers of health care are also employers of the diverse working population. If I'm New York City MTA (Metropolitan Transportation Authority), 10 percent of my employees are minority. Then

I'm certainly going to want to have a plan that's available to my employees . . . [one] that I know will make sure that they get into work everyday."
Anne Beal

"As part of our investigation on the IOM committee, we identified there are significant racial disparities, so we felt strongly that [we could not] do nothing. If anything, we did need to identify patients by their race and ethnicity—the foundation of all future work to eliminate disparities."
Joseph Betancourt

"[On the IOM committee], we did not want to make the data system too burdensome so mainstream health care could not accept it and integrate it. Give main categories when collecting data—five OMB groups [American Indian or Alaska—, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, White]. But give regions and localities flexibility to collect subgroups, like Haitians."
Joseph Betancourt

"Many people are not aware of the changing demographic of their community. Many people don't think that there's a need to collect this information."
Aida Giachello

Data are a tool to engage [hospitals]. This project is going to position the industry to be players.
Denise Love

"It is empowering managers and giving them tools to really manage . . . to provide cost-effective care to a wide variety of people in the community with various needs and backgrounds. It is serving people in a cost-effective way."
Ed Martinez

Provided below is a slide show presentation that can be tailored for your individual hospital.

Overview Presentation

Collecting the Data

Introduction

The recently released report by the National Research Council of the National Academies, "Eliminating Health Disparities: Measurement and Data Needs," recommends that hospitals and health insurers collect standardized data on race and ethnicity using the Office of Management and Budget (OMB) standards as a base minimum. However, experts recognize that greater detail or granularity beyond the OMB categories may be more useful for hospitals and health care organizations. Therefore, we recommend capturing more detailed data on race and ethnicity, which can be aggregated to the broader OMB categories for reporting purposes.

We recommend collecting race and ethnicity information directly from patients. This information should be collected only once and periodically validated. Repeated collection should be avoided to reduce the burden both for patients and for staff responsible for collecting the information. Once this information is collected, it should be stored in an electronic format when possible.

We have designed this toolkit to serve as a resource for hospitals and health care organizations. There are two primary components of race and ethnicity data collection that should be considered standard practice: (1) data should be collected directly from the patient or from a designated representative and (2) a rationale or reason should be provided for why this information is being collected.

We recommend using an open-ended format for collecting race and ethnicity information from patients so patients can use their own words and define up to four racial/ethnic categories. This method has been successfully implemented at Northwestern Memorial Hospital in Chicago. It takes, on average, just 38 seconds to complete data collection using this format. However, we recognize that not all hospitals may be able to implement a system for data collection using an open-ended format. Therefore we provide information for using the broader OMB categories as well as the more detailed Centers for Disease Control Race and Ethnicity Code Sets.

Below you will find information regarding:
• Open-ended format
• Using OMB categories
• Centers for Disease Control categories

The coding sets described below will work for both electronic and paper-based record systems, the important element being consistency in recording and maintaining the record systems with regard to patient race and ethnicity.

Provide a Rationale for Why Race/Ethnicity Information Is Being Collected

Before asking patients to provide information about their racial and ethnic background, provide a rationale for why you are asking for this information. Research conducted at Northwestern University with patients showed that they were most comfortable providing this information when told that it was being used for "monitoring quality of care for everyone."

"We want to make sure that all our patients get the best care possible, regardless of their race or ethnic background. We would like you to tell us your race or ethnic background so that we can review the treatment that all patients receive and make sure that everyone gets the highest quality of care."

It is important to mention that "the only people who see this information are registration staff, administrators for the hospital, and the people involved in quality improvement and oversight, and the confidentiality of what you say is protected by law."

Below, the OMB and CDC Race and Ethnicity Code Sets are provided. The CDC Code Sets are more detailed and provide more granularity under the broader categories. As indicated, hospitals can choose to ask completely open-ended questions allowing patients to "use their own words" and then aggregate this more detailed information into broader categories for analytical purposes. This process enables a hospital to collect more granular information, which may be more useful in planning for interpreter services, developing patient education materials, and understanding patient dietary needs.

Open-Ended Format

We recommend hospitals and health care organizations use an open-ended format when collecting patient race and ethnicity data. Please reference the two staff training presentations provided below as examples.

Staff Training Presentation
Staff Training Question and Answer Response Matrix Presentation

OMB Revised Standards (1997)

In 1997, the Office of Management and Budget (OMB) published Revisions to the Standards for Classification of Federal Data on Race and Ethnicity. For detailed information about the OMB standards, go to www.whitehouse.gov.

First ask question about ethnicity.

Ethnicity

Hispanic or Latino. A person of Cuban, Mexican, Puerto Rican, Cuban, South or Central American, or other Spanish culture or origin, regardless of race. The term "Spanish origin" can be used in addition to "Hispanic or Latino." **Not Hispanic or Latino**

Follow with a question about race. Below are the five race categories used by OMB.

Race

American Indian/Alaskan Native: A person having origins in any of the original peoples of North and South America (including Central America), and who maintains tribal affiliation or community attachment.

Asian: A person having origins in any of the original peoples of the Far East, Southeast Asia, or the Indian subcontinent including, for example, Cambodia, China, India, Japan, Korea, Malaysia, Pakistan, the Philippine Islands, Thailand, and Vietnam.

Black/African American: A person having origins in any of the black racial groups of Africa. Terms such as "Haitian" or "Negro" can be used in addition to "Black or African American."

Native Hawaiian/Other Pacific Islander: A person having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands.

White: A person having origins in any of the original peoples of Europe, the Middle East, or North Africa.

Multiracial

The method for respondents to report more than one race should take the form of multiple responses to a single question and **not** a "multiracial" category.

When a list of races is provided to respondents, the list should not contain a "multiracial" category.

Based on research conducted so far, two recommended forms for the instruction accompanying the multiple response question are "Mark one or more . . ." and "Select one or more . . ." of the listed OMB categories.

Coding Instructions

The following OMB table outlines possible combinations of race and ethnicity and associated two-digit codes. Hospitals and health care organizations can tailor the coding to their individual needs. This sample-coding scheme is provided as an example.
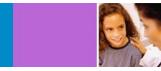
**Centers for Disease Control Race and Ethnicity
Code Set**

The U.S. Centers for Disease Control and Prevention (CDC) have prepared a code set for use in coding race and ethnicity data. This code set is based on current federal standards for classifying data on race and ethnicity, specifically the minimum race and ethnicity categories defined by the OMB described above and a more detailed set of race and ethnicity categories maintained by the U.S. Bureau of the Census. The code set can be applied in both electronic and paper-based record systems.

Within the table, each race and ethnicity concept is assigned a unique identifier, which can be used in electronic interchange of race and ethnicity data. The hierarchical code is an alphanumeric code that places each discrete concept in a hierarchical position with reference to other related concepts. For example, Costa Rican, Guatemalan, and Honduran are each ethnicity concepts whose hierarchical codes

place them at the same level relative to the concept Central American, which is the same hierarchical level as Spaniard within the broader concept Hispanic or Latino.

In contrast to the unique identifier, the hierarchical code can change over time to accommodate the insertion of new concepts. For more information, go to www.cdc.gov.

CDC Code Set - I
CDC Code Set - II

(Upon accessing CDC Code Sets, simply click icon on toolbar to rotate charts vertically.)

Using The Data

Eliminating racial and ethnic disparities in health care is a central issue in overall efforts to improve quality of care. Information on racial and ethnic characteristics of the U.S. population is needed to target quality improvement efforts, identify the nature and extent of disparities, and monitor progress. Measurement, reporting, and benchmarking are critical to improving care. In addition, legal statutes and laws require reporting data by race and ethnicity to monitor discriminatory practices. Ultimately, hospitals and other health care organizations need to be responsive to the communities they serve and a first step toward accomplishing this goal is understanding who the community is and working collaboratively to address problems and concerns.

Access to Quality Health Care

Many experts have called for hospitals and other health care organizations to stratify their quality reports by race and ethnicity. Under the National Voluntary Hospital Reporting Initiative (NVHRI), hospitals are voluntarily reporting on a set of inpatient quality of care measures for three conditions, which include Acute Myocardial Infarction, Heart Failure, and Pneumonia. A number of hospitals are reporting these measures with race and ethnicity information, however the accuracy of this information is questionable. The next logical step may be to ask all hospitals and other health care organizations to stratify their quality measures by accurate race and ethnicity data.

The health system serves three critical functions (Eliminating Health Disparities: Measurement and Data Needs, National Research Council, 2004):

1. Ensuring the health of the population. This is the ability to provide consistent and reliable epidemiological data on the incidence and prevalence of various health conditions and related risk factors among different racial and ethnic populations.

2. Ensuring equitable access to care. Access to care is a prerequisite for entering and staying in the health care system. Available racial and ethnic data have been used to document important differences in access between racial and ethnic groups. More accurate data can also be used to document differences in access within racial groups (e.g. Puerto Rican, Mexican, Somalian, Jamaican, etc.).

3. Ensuring quality of care. Language and cultural barriers can have a negative impact on quality of care. For example, African Americans were nearly twice as likely as whites to report being treated with disrespect during recent health care visits; Hispanics, regardless of language skills, were more likely than other patients to report having difficulty communicating with and understanding their doctors (Collins, Tenney, and Hughes, The Commonwealth Fund, 2002; Doty and Ives, The Commonwealth Fund, 2002). These findings underscore the importance of ensuring culturally competent care to patients by health care providers.

Ensuring Compliance with Civil Rights Laws

Routine monitoring of access, use of services, and key processes and outcomes of care by race and ethnicity is essential to ensuring compliance with civil rights laws and detecting evidence of discrimination. Title VI of the Civil Rights Act of 1964 and related statutes ensure that patients from different groups have equal access to quality care. The Office of Civil Rights and other entities need standardized, accurate, and available data on race and ethnicity to monitor the care that different groups receive.

Being Responsive to Communities

The American College of Physicians position paper on Racial and Ethnic Disparities in Health Care (2004) calls for an ongoing dialogue between hospitals and other health care organizations and surrounding communities to help integrate cultural beliefs and perspectives into health care practices and health promotion activities. Accurate information about race, ethnicity, and primary language can be used to ensure adequate interpreter services, provide relevant patient information materials, and understand dietary practices. Pressing problems in the communities, such as disparities in care, can be addressed more effectively if health care providers and practitioners build the trust of the community by documenting their accomplishments.

Legal Issues

Collecting and reporting race, ethnicity, and primary language data are legal and permitted under Title VI of the Civil Rights Act of 1964.

Links to Reports and Other Web Sites

Racial, Ethnic, and Primary Language Data Collection in the Health Care System: An Assessment of Federal Policies and Practices.

Assessment of State Laws, Regulations, and Practices Affecting the Collection and Reporting of Racial and Ethnic Data by Health Insurers and Managed Care Plans. Under contract to the Office of Minority Health (OMH), the National Health Law Program, Inc. (NHeLP) of Los Angeles is analyzing the status and the perceptions of state laws and actual practices of selected health plans, health insurers, and governing entities regarding collection and reporting of racial and ethnic data.

Click here for more information.

Privacy And Confidentiality

Resources for Information About Privacy and Confidentiality

1. The Institute for Ethics at the American Medical Association has built a toolkit for health care organizations to assess whether their policies, practices, and organizational culture are consistent with protecting patient privacy. The toolkit is consistent with the regulatory framework for protecting privacy that is provided by the Health Insurance Portability and Accountability Act (HIPAA).

The toolkit provides four self-evaluation instruments for health care organizations to use to assess their policies and practices for safeguarding patient privacy and confidentiality including a *Practitioner Survey, Patient Survey, Policy Checklist, and Facility Evaluation Form.* To obtain more information about the privacy toolkit, go to www.ethicalforce.org.

To access the report entitled "The Domain of Health Care Information Privacy: Protecting Identifiable Health Care Informational Privacy: A Consensus Report on Eight Content Areas for Performance Measure Development," go to www.ama-assn.org.

2. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) and the National Committee for Quality Assurance (NCQA) released a joint publication, Protecting Personal Health Information: A Framework for Meeting the Challenges in a Managed Care Environment (1998). The document makes several recommendations and addresses accountability; consent; educating patients and providers about privacy policies, procedures, rights, and responsibilities; technology; providing legislative support; and guiding research.

3. Georgetown University's Institute of Health Policy and Research is sponsoring the Health Privacy Working Group (HPWG). The HPWG has developed a set of principles for health privacy and issued a report entitled Best Principles for Health Privacy. The Health Privacy Project has prepared a practical, comprehensive guide to state health privacy laws. For more information, go to www.healthprivacy.org.

How Can Covered Entities Use and Disclose Protected Health Information (PHI) for Research and Comply with the Privacy Rule?

The privacy rule describes the ways in which covered entities can use or disclose PHI, including for research purposes. In general, the rule allows covered entities to use and disclose PHI for research if authorized to do so by the subject in accordance with the privacy rule. In addition, in certain circumstances, the rule permits covered entities to use and disclose PHI without authorization for certain types of research activities.

For example, PHI can be used or disclosed for research if a covered entity obtains documentation that an Institutional Review Board (IRB) or Privacy Board has waived the requirement for Authorization or allowed an alteration.

The rule also allows a covered entity to enter into a data use agreement for sharing a limited data set. There are also separate provisions for how PHI can be used or disclosed for activities preparatory to research and for research on decedents' information.

Key Points:

1. Deidentified health information, as described in the Privacy Rule, is not PHI, and thus is not protected by the Privacy Rule.

2. PHI may be used and disclosed for research with an individual's written permission in the form of an authorization.

3. PHI may be used and disclosed for research without an authorization in limited circumstances: (1) under a waiver of the authorization requirement, (2) as a limited data set with a data use agreement, (3) preparatory to research, and (4) for research on decedents' information.

Additional Resources

HIPAA
Office for Civil Rights, US Department of Health and Human Services
National Institutes of Health, US Department of Health and Human Services

Staff Training

To ensure that data are collected accurately and consistently, organizations need to invest in training staff so they learn how to collect data from patients, know what to do with the data, and are able to answer any questions patients have about why the data are being collected.

The two presentations listed below were originally developed for staff training at Northwestern Memorial Hospital, but can be individually tailored for your hospital.

Staff Training Presentation
Staff Training Question and Answer Response Matrix Presentation

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Improvement Tools

Useful tools to assist hospitals in their data collection methods include:

Hospital Assessment Survey: To assess current data collection methods.

Validation Instrument: To measure effectiveness of newly implemented data collection methods.

Online Survey: (Coming soon)

Additonal Resources

Who, When, and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals

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Partners/Collaborators

Eliminating Disparities Through Community and Hospital Partnerships

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Community Involvement

Hospitals and other health care organizations are learning that when it comes to delivering health care, it is better to not go it alone. Whether your goal is to increase access to health care for specific populations, serve the uninsured, or target interventions in the community to improve care, it may be more effective if you collaborate with other organizations and stakeholders in the community. Collaboration can help you better align resources with needs, reduce competition, increase effectiveness, and make your results more sustainable. It requires that organizations work outside historical boundaries; dedicate people, skills, and energy to the effort; deal with a diversity of priorities and culture; and think of their organizational plans and operations as part of a system that needs to function seamlessly. ~ *From The Collaboration Primer.* Click here to access the full report.

Additional resources for community involvement and collaboration:

Community Care Notebook: A Practical Guide to Health Partnerships
Association for Community Health Improvement
Public-Private Partnerships to Improve Health Care

Success Stories

We have developed this section to highlight the important work hospitals around the country are doing to improve quality of care. If you are interested in having your hospital included on this page, please contact Debbie Pierce at dpierce@aha.org.

ANMED Health
Kaiser Permanente
Massachusetts General Hospital

Resources

General Information Web sites Related to Disparities in Care

Health Research and Educational Trust

American Hospital Association

Agency for Health Care Research and Quality

Diversity RX

The Commonwealth Fund

The Robert Wood Johnson Foundation

Department of Health and Human Services

National Association of Health Data Organizations

National Association of Public Hospitals and Health Systems (NAPH)

National Public Health and Hospital Institute (NPHHI)

Joint Commission on Accreditation of HealthCare Organizations (JCAHO)

Hospitals, Language, and Culture: A Snapshot of the Nation (JCAHO Project)

Massachusetts General Hospital

Kaiser Permanente

California Pan-Ethnic Health Network

University of Michigan

Henry J. Kaiser Family Foundation

American Medical Association

Patient Centered Communication for Vulnerable Populations (AMA, Institute for Ethics Project)

Centers for Disease Control and Prevention

Health Research and Educational Trust, New Jersey

Articles/Publications

Institute of Medicine: Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care

Commonwealth Fund Report: Who, When and How: The Current State of Race, Ethnicity, and Primary Language Data Collection in Hospitals

Kaiser Family Foundation Report: National Survey of Physicians: Part I Doctors on Disparities in Health Care

Agency for Healthcare Research and Quality(AHRQ): National Healthcare Disparities Report

National Academy of Sciences Report: Improving Race and Ethnicity Data on Health: Report of a Workshop(2003)

Health Forum Journal Article: Working to Eliminate Racial Disparities

Hospital and Health Networks Article: Blind to Bias?

Hospital and Health Networks Magazine Article: Closing The Gap

Health Services Research Journal: Disparities: An Annotated Bibliography

National Public Health and Hospital Institute Report: Serving Diverse Communities in Hospitals and Health Systems: From the Experience of Public Hospitals and Health Systems

Commonwealth Fund Report: Disparities in Patient Experiences, Health Care Processes, and Outcomes, The Role of Patient-Provider Racial, Ethnic, and Language Concordance

Commonwealth Fund Report: Cultural Competencies in Health Care: Emerging Frameworks and Practical Approaches

Health Affairs Article: Addressing racial and ethnic barriers to effective health care: the need for better data

Commonwealth Fund Report: Racial, Ethnic, and Primary Language Data Collection in the Healthcare System: An Assessment of Federal Policies and Practices

Language

Commonwealth Fund Report: Providing Language Interpretation Services in Health Care Settings: Examples from the Field

Health Plans

Health Affairs Article: Eliminating racial/ethnic disparities in health care: can health plans generate reports?

Robert Wood Johnson Foundation Report: Collection of Racial and Ethnic Data by Health Plans to Address Disparities: Final Summary Report Prepared by American's health Insurance Plans

Commonwealth Fund Report: Developing A Health Plan Report Care on Quality of Care for Minority Populations

Tools

Kaiser Family Foundation: Why the Difference Speakers Kit

Family Kaiser Foundation: Key Facts of Race, Ethnicity Medical Care Chart Book

Worlds Apart: A Four-Part Series on Cross-Cultural Healthcare

National Health Law Program Toolkit: Language Services Action Kit

Fellowship/Educational Opportunities

HRET Cultural Competence Leadership Fellowship

Frequently Asked Questions

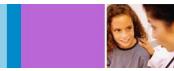### 1. What are health care disparities?

The word disparity can be defined as "the condition or fact of being unequal." Synonyms for disparity include inequality, unlikeness, and difference. Health care disparities can be delineated by describing difference in quality of and access to health care that lead to disparities in health outcomes and may be responsive to improvements in health care.

2. Why is data collection of patients' race, ethnicity, and primary language important?

Data currently available on patients' race, ethnicity, and primary language are severely limited. Often the data that are available are of limited accuracy, completeness, and detail. However, these data are critical

to documenting the nature of disparities in health care and to developing strategies to eliminate disparities and improve quality of care.

3. What is a toolkit?

This toolkit is an easy-to-use resource for health care organizations to implement a systematic method of collecting race, ethnicity, and primary language data.

4. What is the toolkit designed to do?

The toolkit is designed to answer questions about race, ethnicity, and primary language data collection. It provides the answers to the "how to" questions and addresses concerns (legal, privacy) about data collection.

5. How do I use the toolkit?

The toolkit is setup to be user-friendly. The table of contents provides an outline of the type of information available on the toolkit. When you click on a topic area in the table of contents, you will be given a list of the resources available (powerpoint presentations, survey instruments, etc.). The toolkit is designed to guide you through each step.

6. How do I know if I need to implement this type of tool in my hospital?

Given the changing demographics of many communities, we recommend that all hospitals and health care organizations implement a standard, systematic method of collecting race, ethnicity, and primary language data. In addition, many health care organizations need to collect these data for federal or state reporting purposes, and in the near future, accreditation standards for the collection of these data may be put into place.

Contact Us

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Citation